

Changing Stigma Through a Consumer-Based Stigma Reduction Program

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Abstract This study assessed the Anti-Stigma Project workshop, a contact/education intervention developed by On Our Own of Maryland, Inc. and the Maryland Mental Hygiene Administration. Two separate randomized controlled trials administered pre- and post-test questionnaire assessments. One included people with mental illness ($N = 127$) and a second included mental health providers ($N = 131$). Post-intervention, people with mental illness were more aware of stigma, had lower levels of prejudice, and increased belief in recovery. Providers were more aware of stigma, had lower levels of prejudice, and increased concurrence in self-determination of people with mental illness. Increasing providers' stigma awareness and recognition can promote higher quality service delivery. Increasing stigma awareness and recognition for people with mental illness can foster confidence in overcoming psychiatric disabilities. Using a participatory action research team, our protocol included extant and newly developed stigma change tools. Organizations seeking to conduct effective evaluation studies should consider collaborative processes including the expertise of affected constituents.

Keywords Anti-stigma groups · Consumer research · Stigma · Participatory action research

Introduction

Combating the stigma of mental illness is a public health priority that has received considerable attention around the world, including the World Psychiatric Association's interventions and evaluations to reduce stigma involving 27 countries on six continents (Thornicroft et al. 2009). Initiatives of this magnitude signal that stigma is a significant social problem, one that compromises psychological health and interrupts the pursuit of life goals. Prejudicial and discriminatory behaviors and practices stemming from stigmatizing beliefs and attitudes preclude people with mental illnesses from obtaining work (Cechnicki et al. 2011; Sharac et al. 2010; Tsang et al. 2003) and housing (Corrigan et al. 2003a, b; Link and Phelan 2001; Wahl 1999). As a result, people with mental illness miss out on opportunities to fully participate in society.

To confront stigma's consequences, three main intervention methods have been used with different audiences: protest, education, and contact (Corrigan and Penn 1999). Protest raises awareness about prejudice and unfair situations (Corrigan et al. 2001a, b). Education increases knowledge about mental health by replacing erroneous myths with facts (Watson et al. 2004). Contact uses people with personal mental health challenges in either video (Corrigan et al. 2007) or in vivo (Rusch et al. 2008) presentations. Contact and educational strategies have been shown to be more effective than protest (Corrigan and Penn 1999). A recent meta-analysis including outcome data from 38,000 research participants from 79 studies of public stigma change showed that contact-based strategies led to

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stronger outcomes than educational methods (Corrigan et al. 2012). Protest was largely absent from the literature; nearly all studies evaluated contact and/or education strategies. Meta-analysis results revealed that both education and contact programs relative to control group outcomes produced significant changes in both attitudes and behavioral intentions but, contact yielded stronger outcomes by more than threefold over the effect sizes for education. The meta-analysis demonstrates that public stigma change programs that deliver messages via interpersonal contact from a person with a mental health condition are much more likely to have a larger impact than educational strategies.

Some initiatives have been designed for the general public to improve their attitudes toward mental illness (Thornicroft et al. 2009) while other programming strives to increase treatment-seeking behavior (e.g., PSAs; SAMHSA 2011). Other interventions have set out to reduce stigma by targeting future health care providers such as medical or nursing students (Schmetzer and Lafuze 2008; Sadow and Ryder 2008) and mental health care providers (Cook et al. 1995). Schulze (2007) reviewed studies from around the world to show that mental health providers possessed negative attitudes that are on par with the general public, despite their advanced training about psychiatric disorders. The potential impact on the provision of mental health treatment and services underscores the importance of targeting specific audiences, such as mental health care providers, for anti-stigma interventions. Another group of people have lived experiences themselves. People with psychiatric disabilities who internalize stigma may experience serious consequences including diminished self-esteem, self-efficacy, personal empowerment, and belief in recovery (Corrigan et al. 2006; Livingston and Boyd 2010; Overton and Medina 2008; Wahl 1999). Some interventions have sought to counteract these consequences by challenging self-stigma and promoting personal empowerment (Borras et al. 2009; Link et al. 2001; MacInnes and Lewis 2008).

The present study evaluated a contact/education intervention, the Anti-Stigma Project workshop (ASP), which was developed in 1993 by On Our Own of Maryland, Inc. (a statewide mental health consumer education and advocacy group) and the Maryland Mental Hygiene Administration. The ASP was designed to educate participants in a small group setting (about 10 participants) about mental illness stigma's impact on people with mental illness, families of people with mental illness, and mental health providers. Two co-facilitators began by introducing themselves and described the workshop's purpose. Next, facilitators explained two rules (confidentiality and mutual respect) and invited participants to suggest other rules. Facilitators then explained ASP's history and mission to orient participants to the workshop. A definition of public

stigma was elicited through group discussion and groups' initial definitions were compared and contrasted to the Webster's dictionary definition. Next participants found a partner and were instructed to discuss an example of when they felt stigmatized. Interactive group discussion proceeded when stories of stigma were shared and group reactions were elicited. Then the group watched a video about public stigma's impact in the design, delivery, and receipt of mental health services. The video was professionally created for On Our Own of Maryland to reinforce ASP's delivered content in another medium to present the experiences of stigma from the perspectives of mental health administrators and providers, mental health consumers, and family members of people with mental illness. Interactive group discussion was elicited in response to the video and co-facilitators segued group discussion into ways to combat public stigma on both a personal and systemic level. Overall, this group-based intervention is designed to raise awareness of overt and subtle mental illness stigma through interactive discussion, group exercises, video presentation of stigma followed by audience analysis, and exploration of audience elicited examples of stigma.

This study evaluated the impact of ASP on people with mental illness and service providers participating in the workshop. Hypothesized benefits for people with mental illness attending the ASP included stigma reduction, increased stigma awareness, and an increased belief in recovery from mental illness. Hypothesized benefits for service providers included stigma reduction, increased stigma awareness, and improved beliefs about self-determination and recovery for people with mental illness.

Methods

This study examined the ASP through administration of two separate randomized controlled trials (RCTs) with pre-test and post-test questionnaire assessments. One RCT was conducted with people with mental illness concurrently using mental health services such as medication management, case management, or employment support. The second was done with providers of these kinds of mental health services. A provider was defined as a person legally qualified to provide mental health services.

Recruitment was accomplished by contacting the director of Maryland mental health facilities. Advertising was subsequently facilitated with a flyer. Selected study sites had not received the ASP workshop within the past 3 years. Research assistants facilitated either a telephone or in-person screening to ensure that each participant had never attended the ASP workshop.

Table 1 summarizes demographics of people with mental illness and providers. The 127 people with mental

illness were more than half women, about half identified as being single/never married, and more than two-thirds had at least a high school diploma. People with mental illness had an average age of about 45 years. They were about 40 % European American and 40 % African American. One hundred thirty-one providers were more than 80 % women, about half reported being married, and more than 90 % had a graduate degree. Average age of providers was also about 45. They too were mostly European American or African American. Analyses were run to assess demographic differences between intervention and control groups for the two studies. The only significant difference was that the consumers' intervention condition had about twice as many African Americans as European American participants compared to the control group which contained about twice as many European American as African Americans, $\chi^2(4, N = 127) = 12.98, p < .05$. Further analyses did not show any significant differences in consumer outcome measure endorsement across conditions from pre-test to post-test based on racial demographic differences for either the attribution questionnaire [$F(3, 114) = 0.74, p > .50$] or recovery assessment scale [$F(3, 79) = 0.139, p > .90$].

Consenting participants completed questionnaires at baseline and then were randomly assigned to either the ASP or a control condition. Randomization was determined a priori by use of a random numbers table to ensure systematic assignment to condition. Two experienced facilitators administered a standard, 3-h ASP workshop. The leaders facilitate discussion about stigma by using participants' personal experiences with stigma bolstered by media analysis, interactive exercises, and group brainstorming. Program participants identify stigma's impact on the design, delivery, and receipt of mental health services, and devise ways to combat stigma on both a personal and systemic level. Control condition participants attended either "Steps to a Healthier You" (people with mental illness only) or "Sleep and YouTube" (providers only) for a 3-h period coinciding with the delivery of the ASP. Neither control condition discussed mental health. A fidelity measure monitored facilitators' adherence to the ASP manual; a 96.5 % adherence rate was found. Post-test questionnaires were administered upon conclusion of the assigned condition. Compensation for questionnaire completion was a \$20 Visa gift card. Providers received a \$20 Visa gift card and continuing education credits (CEUs) for their participation.

All participants completed the Attribution Questionnaire (AQ-9; Corrigan et al. 2003) at pre-test and post-test. The AQ-9 contains nine questions that assess affective, behavioral, and cognitive reactions to a vignette about Harry, a man with schizophrenia, using a 9-point Likert scale (9 = strongly disagree). An example item is,

Table 1 Demographic characteristics of people with mental illness sample (N = 127) and providers of mental health services (N = 131)

Variable	People with mental illness Mean (SD)/%	Providers Mean (SD)/%
<i>Sex</i>		
Female	52.8	83.2
Male	46.4	16.8
Did not specify	0.8	0
Age	45.3 (11.4)	45.4 (11.4)
<i>Ethnicity</i>		
African American	38.6	35.9
Asian/Pacific Islander	0.8	2.3
European American	43.3	58
Native American	10.2	0
Other	5.5	3.1
Did not specify	1.6	0.7
<i>Marital status</i>		
Single/never married	55.1	28.2
Married	10.2	51.9
In a long term relationship	7.1	6.1
Widowed	6.3	2.3
Separated/divorced	19.7	11.5
Did not specify	1.6	0
<i>Educational attainment</i>		
Some high school	30.7	0
High school diploma	28.3	1.4
Some college	26.8	3.1
Undergraduate	4.7	3.1
Graduate	7.1	92.4
Did not specify	2.4	0
<i>Employment status</i>		
Full time	2.4	87.8
Part time	11.8	9.2
Unemployed	63.8	0
Attending school	2.4	0
Other	18.9	2.3
Did not specify	0.7	0.7

"I would feel pity for Harry." One item, about willingness to help, was reverse scored to compute total scores with higher scores representing greater stigma towards individuals with mental illness. Acceptable internal consistencies were obtained for people with mental illness (0.73) and providers (0.71).

The Awareness Questionnaire (AwQ) was completed by all participants at post-test. This measure was collaboratively created by a Participatory Action Research team and was based upon focus group participants' (i.e., people with mental illness, providers of mental health services, and family members of people with mental illness) input

regarding ASP's impact. The AwQ contains seven items that assess the recognition of stigma within the mental health system, and its impact on people with mental illness, family members of people with mental illness, and mental health providers by using a Likert Scale (7 = strongly agree). An example item is, "I recognize that stigma is a problem in the mental health system". Higher total scores represented stronger agreement, suggesting greater awareness and recognition of mental illness stigma. Cronbach's alphas were acceptable for people with mental illness (0.68) and providers (0.70).

All participants also completed the error choice test (EC) at post-test. The EC on mental illness stigma was written to discretely measure stigma by circumventing social desirability effects and is therefore presented as a knowledge test (Michaels and Corrigan 2013). The problem of social desirability is people's penchant to endorse responses they believe conform to appropriate cultural mores in lieu of otherwise reporting their "true belief" (Tourangeau and Yan 2007; Whitley 2002). Test content maintained the knowledge test façade with items written upon course of illness (e.g., symptoms, etiology, prognosis, treatment, epidemiology) and interpersonal issues (e.g., theft, homelessness). For this EC, items used either numerical or True/False answers (Hammond 1948). To maintain consistency throughout the EC, each item has only two answer choices. Each item assesses prejudice; participants scored one point for each stigmatizing answer and zero points for each non-stigmatizing answer. Total scores can range from zero to 14 with higher scores representing greater prejudice toward people with psychiatric disabilities.

This study also evaluated social inclusion of people with mental illness. Social inclusion is a societal ideal of allowing access to economic, interpersonal, spiritual, and political resources available to all adults seeking to accomplish their personal goals (Leff and Warner 2006). Important concepts in the mental health system of recovery and self-determination have influenced ideals of social inclusion more broadly known as affirming attitudes (e.g., a belief that people with psychiatric disabilities can recover and be self-determined). The following measures assessed recovery and self-determination to evaluate ideals comprising social inclusion.

People with mental illness completed the Recovery Assessment Scale (RAS) at pre-test and post-test. The RAS (Corrigan et al. 1999, 2004) contains 22-items that assess people with mental illness' beliefs in their ability to overcome psychologically related problems in both intra-personal and interpersonal domains using a Likert Scale (5 = strongly agree; e.g., I have my own plan for how to stay or become well). Higher total scores represent greater agreement in their perceived ability to recover from their mental illness. Internal consistency (0.94) for the RAS was excellent.

To assess providers' affirming attitudes regarding overcoming psychiatric health problems, the RAS was modified to create the Recovery Scale (RS; Corrigan et al. 2012). The RS was completed at pre-test and post-test and contains 13 Likert Scale items (9 = strongly disagree) that assess the perceived recovery potential of people with mental illness. An example item is, "People with mental illness are hopeful about their future". Higher total scores represent greater disagreement with the potential for people with psychiatric disabilities to overcome their mental health problems. Internal consistency (0.73) for the RS was acceptable.

Providers' affirming attitudes were also assessed with the Self-Determination Scale (SDS; Corrigan et al. 2012) at pre-test and post-test. The SDS contains 14 Likert Scale items (9 = strongly disagree) presenting a wide variety of typical life goals that the general public holds in high esteem (e.g., work, home ownership). On the SDS, endorsements represent the degree to which people with psychiatric disabilities should pursue certain life goals. An example item is, "Harry should pursue a full-time job". Higher total scores represent stronger disagreement and indicate greater social restriction for people with psychiatric disabilities. A Cronbach's alpha of 0.86 indicated acceptable internal consistency.

All study methods and materials were reviewed and approved by the Institutional Review Boards of both the Illinois Institute of Technology and the Maryland Department of Health and Mental Hygiene prior to data collection procedures. There are no conflicts of interest for any author. All authors assume responsibility for manuscript content.

Results

Table 2 summarizes means and standard deviations for the outcome measures. People with mental illness completed the AQ-9 and RAS at both pre-test and post-test. People with mental illness and providers completed the AwQ and EC only at post-test. Providers completed the AQ-9, SDS, and RS at both pre-test and post-test. Separate analyses were conducted for people with mental illness and providers. Analyses conducted for measures administered at both pre-test and post-test were a repeated measures 2×2 ANOVA (group by trial). For measures administered only at post-test, ANOVAs were used.

For people with mental illness, the ASP produced a significant group effect on the AwQ, [$F(1, 123) = 16.46, p < .001$]; people with mental illness attending the ASP were more aware of stigma. On the subtle stigma measure (the EC), there was a group effect for people with mental illness, [$F(1, 123) = 6.75, p < .01$]. ASP participants endorsed lower levels of prejudice than people with mental illness in the control group. Finally, the ASP yielded a

Table 2 Immediate benefits conferred to people with mental illness and providers attending the ASP compared with controls

Measure	People with mental illness				Providers				F (df)	F (df)
	ASP Pre-test X (SD)	Control Pre-test X (SD)	ASP Post-test X (SD)	Control Post-test X (SD)	ASP Pre-test X (SD)	Control Pre-test X (SD)	ASP Post-test X (SD)	Control Post-test X (SD)		
AQ-9	33.5 (11.9)	37.7 (14.3)	28.5 (13.2)	33.3 (14.8)	23.0 (7.7)	23.4 (9.6)	20.5 (8.6)	22.4 (9.1)	2.66 (1,128)	2.66 (1,128)
AwQ			35.0 (6.2)	29.9 (7.9)			36.7 (4.9)	29.7 (5.8)	56.1 (1,129)***	56.1 (1,129)***
EC			6.2 (2.4)	7.3 (2.1)			4.9 (1.9)	6.2 (2.3)	10.5 (1,128)***	10.5 (1,128)***
SDS					57.2 (16.8)	54.1 (16.7)	46.4 (15.9)	49.5 (16.8)	7.5 (1,96)**	7.5 (1,96)**
RS					52.0 (12.8)	49.9 (11.7)	45.4 (13.7)	46.8 (13.6)	3.62 (1,97)	3.62 (1,97)
RAS	82.3 (14.6)	86.7 (12.6)	86.8 (13.0)	84.6 (14.5)					8.2 (1, 86)**	8.2 (1, 86)**

AQ-9 = Attribution Questionnaire 9-Item; AwQ = Awareness Questionnaire 7-Item (Post-test only); EC = Error Choice Test of stigma (Post-test only); SDS = Self-Determination Scale (Providers only); RAS-13 = Recovery Scale (Providers only); RAS = Recovery Assessment Scale (Consumers only); X (SD) = Mean, standard deviation; F (df) = F-test value (degrees of freedom)

* $p < .05$; ** $p < .01$; *** $p < .001$

significant condition x time interaction on the RAS [$F(1, 86) = 8.22, p < .01$]. This meant personal recovery was significantly fostered in people with mental illness receiving the workshop.

For providers, The ASP produced a significant group effect on the AwQ, [$F(1, 129) = 56.12, p < .001$]. Indicating that providers were more aware of stigma than the control group. On the subtle stigma measure (the EC), there was group effect for providers [$F(1, 128) = 10.54, p < .001$]. The results indicate that providers attending the ASP exhibited lower levels of prejudice toward people with psychiatric disabilities after the workshop. The ASP yielded a significant condition x time interaction on the SDS [$F(1, 96) = 7.52, p < .01$] suggesting that providers attending the workshop had significantly decreased negative beliefs regarding the acceptability of a wide variety of personal goals for people with psychiatric disabilities. Finally, the ASP did not produce a significant condition x time interaction on the RS [$F(1, 97) = 3.62, p = .09$]. Results indicated that providers' opinions were not significantly improved regarding the potential for recovery from mental illness.

Discussion

The purpose of this study was to evaluate the effectiveness of On Our Own of Maryland's ASP for people with mental illness and mental health providers. The ASP increased awareness of systemic stigma for both people with mental illness and providers. Stigmatizing attitudes were also lowered for people with mental illness and providers. Interestingly, this change was detected with the subtle stigma measure, which was designed to circumvent social desirability, rather than an explicit measure of stigma. The ASP workshop also positively impacted affirming attitudes. For people with mental illness, the workshop significantly fostered a belief in their ability to overcome their mental health challenges. On the other hand, providers' views about recovery from mental health problems showed a non-significant trend toward improvement, an intriguing finding given that people with mental health conditions attitudes toward recovery showed significant improvement. Providers' attitudes about self-determination of people with mental illness were positively impacted. Taken together, the ASP raised awareness, improved affirming attitudes, decreased stigma, and fostered a sense of personal recovery.

There were limitations to this study. Mental health providers were recruited by advertising free CEUs for study participation. Hence, providers opting to participate in this study may have a greater interest in learning about social issues surrounding psychiatric disabilities thereby being

more open to learning how to improve the mental health system. Second, the sample of people with mental illness was recruited from mental health facilities and may have had exposure to other anti-stigma initiatives within the Maryland mental health system. Therefore, the ASP may have a stronger or different impact on people with psychiatric disabilities who have had less contact with the mental health system. On a related issue, psychiatric diagnostic data was not collected in this study. Future research might consider assessing whether stigma elimination programs have a similar impact on people with different mental health conditions. Fourth, two measures, the Awareness Questionnaire and the EC, were only administered at post-test to avert concerns of learning effects. Since these measures were not administered at pre-test, such differences may not be entirely attributable to the intervention, as differences may have existed at baseline. Finally, this study used self-report measures that assess ASP's impact. Measurement of attitudes and behavioral intentions are frequently used; however, observable behavioral change of people with mental illness and providers would demonstrate stronger evidence of actual change (Corrigan and Shapiro 2010; Link et al. 2004). This type of measurement was not obtained in this study, as it is prohibitively expensive and therefore not feasible. Future research with contact-based anti-stigma interventions should consider evaluating the longevity of attitudinal changes and what behavioral changes that participants make in their lives in the long term. Toward this longitudinal assessment goal, a recent meta-analysis of public stigma interventions highlights the relative dearth of published follow-up data (Corrigan et al. 2012). Future public stigma interventions should obtain follow-up data so that inferences might be made about sustained impact.

Despite these limitations, this study indicates that the ASP has significant benefits. Providers with greater awareness of stigma may have improved attitudes toward people with mental illness, which could foreseeably counteract stigma's adverse consequences through their interpersonal conduct. For people with mental illness, a greater comprehension of stigma and recovery may provide the tools necessary for self-advocacy and overcoming the consequences of stigma. Finally, this study demonstrated that a participatory process involving a variety of constituents in a public health system can result in the development of an effective evaluation study. Mental health organizations seeking to conduct effective evaluation studies should consider using collaborative processes that includes the expertise of affected constituents (Corrigan and Shapiro 2010).

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